

## Acknowledgements

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## References

- 1 Ravelingien A, Mortier F, Mortier E, *et al*. Proceeding with clinical trials of animal to human organ transplantation: a way out of the dilemma. *J Med Ethics* 2004;**30**:92–8.
- 2 Mill JS. *On liberty*. Harmondsworth: Penguin, 1982.
- 3 Ten, CL. *Mill on liberty*. Oxford: Clarendon, 1980.

## Research and patients in a permanent vegetative state

The argument that a permanent vegetative state (PVS) equates to death because it marks the death of the person is not a new one, but I wonder whether Ravelingien *et al*<sup>1</sup> need to regard those in a PVS as dead to make a case for animal to human transplantation trials taking place in such people. It is not an argument likely to convince anyone who refuses to accept that only human persons have inherent value, dignity or a right to life, and the arguments on both sides have been well rehearsed, with no sign of reconciliation. My own view is that people in a PVS are still alive, albeit with a poor quality of life. I see no objection in principle to the proposal that competent people can decide, in advance, to participate in research when they become incompetent. At the present time, it is generally accepted that an advance refusal of consent should be respected. Some controversy exists on whether someone can insist on treatment in advance, but in Ravelingien *et al*'s<sup>1</sup> paper, what is being proposed is not that people can insist on becoming research participants, but rather that they can signal a willingness to become such a participant in the future. Indeed, this principle can be extended to competent people such as those with early onset of Alzheimer's disease and degenerative neurological conditions, who could agree in principle to the kinds of research, broadly conceived, they would be willing to be included in if and when they become incompetent in the future. Helping others by taking part in clinical research is undoubtedly a good way to live out what may be years in a PVS or other less-compromised states. It may even help those for whom such a life is a virtual certainty to find meaning for the future they are destined to live.

My endorsement of Ravelingien *et al*'s<sup>1</sup> proposal is, however, cautious and based on three assumptions: (1) people in a PVS are still alive and they should not be regarded as dead; (2) PVS can be diagnosed accurately and the procedure for diagnosing it is generally accepted and uncontroversial; (3) a PVS is a permanent state and not one from which a patient, however remote the chance, can make any recovery. If this is not the case, then the solution given by Ravelingien *et al*<sup>1</sup> is less compelling as someone who recovers

generates all the ethical problems that would be present if volunteers in non-PVS were used—namely, that severe restrictions on lifestyle would have to be imposed for public health reasons, effectively making it impossible to withdraw consent in the normal sense of the concept.

I do, however, think that there are practical problems with the proposal; hence the caution. The most obvious of these is that few, if any, people are likely to have advance warning that they will eventually end up in a PVS. For this proposal to work, therefore, many thousands of people will have to give their agreement, in principle, to be enrolled to the study should they be unfortunate enough to enter a PVS. A general agreement to donate our body to science or medical research will not do: people in a PVS are not dead, and the research will probably last for many years, with all the attendant strains on the participant's family. In such circumstances, however, keeping someone in a PVS alive so that they can take part in research does not raise the usual questions about the use of public resources, as I also assume that the research would be funded by a research body or that the health service is willing to fund such animal to human transplantation trials in the light of possible future savings for the service as a whole. Accordingly, such research does not pose any burden on the health service, or if it does, such a burden has been considered beneficial in the longer term. Either way, resource concerns can be dismissed. They may, however, re-appear once the trial is over if the research participants are still alive, particularly if they are also unwilling to specify in advance that they refuse treatment such as artificial nutrition at the conclusion of the study. Is such an unwillingness a justifiable exclusion criteria for entry into the trial?

Accepting that people in a PVS are alive would also help to resolve some of the issues raised in relation to the role of relatives. Ravelingien *et al*<sup>1</sup> are unclear about whether relatives should be able to veto the decision of the person in a PVS. On the one hand, they give weight to the likely and particular emotional reactions of the relatives to the procedures being carried out (and presumably the decade or more of life in a PVS required for such a trial to be completed). On the other, they refer to occasions when the wishes of the living are not permitted to override those of the dead—such as, in the disposal of property through a will. How people choose to live their lives, however, is not something that relatives—even close relatives such as parents or children—can justifiably veto. How someone chooses—all things being equal—to live out their life in a PVS is a matter for them alone, just as how they lived their life before the PVS was. Of course, people are obliged to consider the effect of their lifestyle choices on others, particularly on those closest to them, but even when they fail to do so, relatives cannot veto these choices, and sometimes people make decisions that, while taking into account the harmful effects they may have on others, they believe to be right on balance. Entering a closed religious order, emigrating, and divorcing all occur despite the losses and discomfort of those closest to us, and those we hurt or disappoint have to adjust their expectations and feelings about us accordingly. Given that there is no practical burden to the relatives—having to provide daily care to the person in a PVS, for instance—it is

difficult to see what claim they have to veto the decision to take part in the research. So, if we take the view that patients in a PVS are still alive, it is not a matter of suggesting that the interests of relatives (the living) should be permitted to override those of the dead, but rather that the living can make choices about how to live their lives that are not subject to an automatic right of veto from their relatives, even if these choices prove hard for relatives to live with.

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## Reference

- 1 Ravelingien A, *et al*. Proceeding with clinical trials of animal to human organ transplantation: a way out of the dilemma. *J Med Ethics* 2004;**30**:92–8.

## Relatives of the living dead

Death has a social meaning in every culture. It is not something that concerns only the person who dies, but also his or her family, friends and other people in the community. Most people have an idea of what counts as a good death—for the person concerned or for those who survive. Some people would prefer to die suddenly and painlessly, in their sleep if possible. But for many people, a good death is a process in which they gradually lose their hold on life, become reconciled to their end and say goodbye to their loved ones. From the point of view of relatives and friends, a good death is likely to be one in which they have a chance to show their feelings for the dying person and to become reconciled to their loss as the patient's life fades away. At the end of this process, there is a dead body that can be put to rest in an appropriate ceremony, and then those still surviving are free to begin learning to live without the dead person.

Problems, ethical and social, arise when the social understanding of death and how the living should relate to the dead and dying clash with medical definitions of death, or the perception of dead or dying people as a medical resource. This clash is more serious in some cultures than in others. In Japan, for example, where relatives think it is important to maintain a relationship with a dying person until all signs of life cease, brain death is not accepted as sufficient to bring the relationship to an end and, as a result, taking organs from a brain-dead person is generally regarded as unacceptable.<sup>1</sup> In Western countries, most people are willing to accept that brain death constitutes the end of a person's life and thus the end of their relationship with that person, but there is a certain amount of unease about taking organs from such a person. In some countries, the wishes of the relatives prevail even in cases where the brain-dead person had consented to donation.

If those who have entered a permanent vegetative state were to be used as subjects for xenotransplantation, as suggested by Ravelingien *et al*,<sup>2</sup> the tension that exists even in Western societies between social ideas on how to relate to the dying and medical perceptions of death (or being "as good as dead") would reach the breaking point. Consider what relatives will be expected to